Conceptual Issues in Measuring the Burden of Skin Diseases

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How can we monitor the health of a population?

How can we determine the effects of a specific disease on that health?

How can we compare the health effects of many diseases, to determine which should be addressed?

Health is multidimensional, and determining how health is affected by disease is therefore complex. Answering these questions requires rigorous research inquiry based on established techniques in epidemiology, biostatistics, economics, psychometrics, and decision analysis. In addition to their scientific interest and significance to our patients and practices, these questions are important to the conduct and goals of our research efforts, and to the public health.

This focused issue of the *Journal* is devoted to studies that address the burden of skin diseases. In this commentary, we will provide a conceptual basis for these studies. We will discuss what is meant by burden of disease, and propose a taxonomy, or a system to organize the various components of disease burden. We will identify methodological difficulties that arise not only in measuring burden of disease, but also in comparing the burdens of different diseases. We will describe distinct challenges that face us in measuring and assessing the significance of the burden of *skin* diseases in particular, which generally do not affect survival or functioning, but which nonetheless can greatly affect patients' mood and psychological functioning. We will end by discussing current metrics for global burden of disease in populations, suggesting that these commonly cited measures may be inadequate for assessing the burden of skin disease.

The interest of the *Journal* in this topic reflects a widespread and growing international trend. When we searched MEDLINE for the term "burden of disease", we found a dramatic increase over the last 40 y in the number of papers accessed (Table I). This increase is due to a powerful confluence of political and academic initiatives. Scholarly work examining the burden of disease is based on and parallels long-standing work on *cost of illness* (Rice *et al*, 1985), reflecting a growing scrutiny by governments and international consortiums in the financial repercussion of various illnesses. In the early 1990s, the World Bank and the World Health Organization (WHO) moved beyond monetary costs only and undertook the Global Burden of Disease enterprise to learn about the contribution of different diseases to ill-health (Murray and Lopez, 1997). In the mid-1990s the Institute of Medicine proposed that disease-specific research funding by the National Institutes of Health be compared with the burden of specific diseases or disease groups on which the individual Institutes focus (Gross *et al*, 1999). Thus, there were strong scholarly and financial incentives to measure the burden of diseases.

Defining Burden of Disease

For the purposes of this commentary, we define burden of disease as the effects of disease on overall health. The burden of disease cannot be adequately expressed as a single number. Traditional measures of mortality and incidence are important, but provide an incomplete picture. For example, the impact of disease on quality of life and ability to function are not reflected in the incidence and mortality numbers. As with diseases of many organ systems, the burden of skin diseases can be assessed from the viewpoints of the person, the family, and society. Atopic dermatitis illustrates these multiple perspectives. Atopic dermatitis is a common childhood chronic disease, affecting 5%–10% of children (Kemp, 1999), and causing broad and significant effects on the well-being and development of afflicted children (Lawson *et al*, 1998). In addition, families of children with moderate or severe atopic dermatitis reported significantly higher effects of the child's eczema on the family's economic and psycho-social well-being than did families of children with diabetes (Su *et al*, 1997). Also, atopic dermatitis is a financially costly disease for society (Kemp, 1999). Thus, multiple perspectives of the burden of atopic dermatitis can be measured accurately, and compared informatively with those of other conditions.

A Taxonomy of Burden of Disease

A practical conceptual framework for the components of burden of disease is presented in Fig 1. Components of burden of disease can be either economic or non-economic. Economic burdens include costs that are direct (i.e., for which funds can be paid, such as health services used), or indirect (i.e., for which charges are not routinely

Table I. Number of citations in PubMed for search term "burden of disease", by decade

Year	Number of citations
1961–1970	0
1971–1980	4
1981–1990	12
1991–2000	284

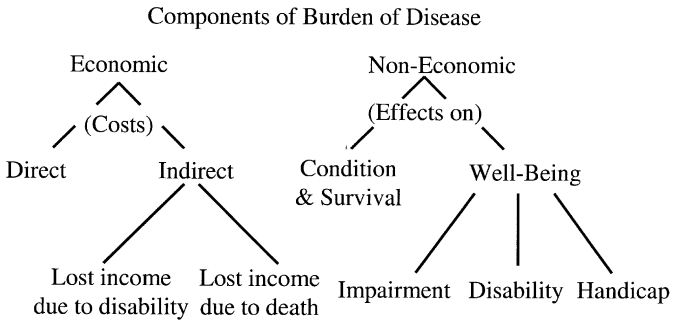

Figure 1
Taxonomy for burden of disease.

assigned, such as lost income due to disability or premature death). Non-economic burdens are the effects of a given disease on survival, and on the well-being of the population. The effects of a disease on an individual's well-being can be conceived as related to the impairment, disability, or handicap caused by the disease (Patrick, 1994). Using WHO terminology, *impairment* refers to the biological properties of the disease (e.g., the degree of scaling caused by psoriasis). *Disability* refers to diminished functioning caused by disease (e.g., inability to use one's hand because of psoriasis involving the palms). *Handicap* refers to the effects of the disease on one's overall quality of life.

Methodological Issues in Measuring Burden of Disease

Measurement schemes and tools have been developed for each of these components of burden of disease. Economic aspects are usually measured in money spent or in resources utilized. Simple counting of the number of cases of a disease is an important early step in assessing burden, and can be expressed as incidence (number of new cases, typically expressed as a ratio to the size of the population at risk) or prevalence (the proportion of the population that is affected). Death is a catastrophic consequence of disease, and is measured primarily by mortality rate. These rates are typically age adjusted to a standard population; hence, if inferences are to be drawn from the relative magnitudes of mortality rates, the standard used for age adjustment must be specified to avoid misleading conclusions. For example, the 1998 mortality from melanoma in the United States (per 100,000 per y) was 4.1 and 1.8 for men and women, respectively, when the 2000 USA standard was used, but only 2.7 and 1.2 when the 1940 USA standard population was used. Misleading inferences can also result from uncritical acceptance of government statistics without evidence of accuracy of those numbers. Examples include data about non-melanoma skin cancer and cutaneous lymphoma, which have been shown to have large inaccuracies (Weinstock *et al*, 1992; Weinstock and Reynes, 1998). Another measure related to mortality rate is "years of life lost". Here care must be taken to scrutinize the method by which this is calculated, since the use of different methods can mislead (Weinstock, 1993).

Since most skin diseases are not associated with substantial mortality, measures of morbidity assume greater importance for measurement of burden of disease (Weinstock and Chren, 2003). Well-being, however, is not easily "counted". Because the components of well-being are either clinical phenomena (e.g., extent of disease) or abstract concepts (e.g., quality of life), precise measurement has required the application of scientific measurement principles from clinimetrics (Feinstein, 1987) and psychometrics. These techniques have been used to design disease severity measures (to assess impairment), disability measures (to assess diminished functioning), and quality-of-life instruments (to assess handicap). Because dermatological diseases only uncommonly affect laboratory values, measures of disease severity typically involve clinician ratings of the clinical characteristics of disease, such as degrees of scaling, or extent of body surface area involved. Disability measures determine patients' ability to perform certain functions, either by direct observation of the performance, or by report. Quality-of-life measures assess patients' experiences and perceptions of disease, and therefore consist of questionnaires in which patients respond to items that inquire about aspects of quality of life, such as symptoms, functioning, and psychological state. Responses to items are typically assigned numeric values; total scores are calculated based on the responses to the items, and are most often reported as a profile of subscores corresponding to the various aspects of quality of life.

Some measures of well-being are intended to measure the *value* a person attaches to life with a disease, assessing patients' (or peoples') preferences for different health states. One example of these preference measures is *utilities*; utilities are typically measured by determining respondents' willingness to trade off time lived with a disease for disease-free life, or their willingness to pay to avoid having a disease. One advantage of utilities is their interpretability: regardless of disease, they are generally reported on a 0 (death)–1.0 (healthy life) scale. Also, because utilities are reported as single scores (rather than a profile of scores), they are useful for cost-effectiveness studies in which single-metric quality-of-life scores are needed. Utilities can be difficult and time-consuming to elicit, however, and their validity has been questioned (Giesler *et al*, 1999). Other examples of value-adjusted metrics include health-adjusted life years and disability-adjusted life years. How the "value" is determined, whose responses are being assessed, and how the adjustment for value is made have important implications for assessing the effects on well-being of different diseases (Cohen, 2000).

Challenges in Measuring Burden of Disease

Measuring complex aspects of health is challenging. As with all measurement tools, instruments to assess the components of burden of disease must at a minimum be reliable (i.e., have a high signal-to-noise ratio) and valid (i.e., measure what they are intended to measure) (Chren, 2000).

In addition, we face unique challenges in attempting to describe and measure the burden of skin disease. First, the term "skin disease" is ambiguous, both with respect to the term "skin" and the term "disease." Biological conditions often involve multiple organ systems, and there may be no consensus on whether they primarily or predominantly concern the skin. For example, thermal burns, decubiti, and melanoma are common conditions often treated primarily by surgeons or oncologists rather than dermatologists, and, when they lead to death, it is because of their effect on other organ systems. Lupus is an example of a disease that may be exclusively cutaneous or have no cutaneous manifestations. Further, there is disagreement about whether certain conditions (e.g., skin aging, striae, male-pattern baldness, "oily" facial skin) should be considered diseases at all, and whether the consequences of undesirable manifestations of what is arguably normal variation in the human condition should be counted in the burden of disease. Some of the disagreement relates to who is participating in the debate. A substantial portion of lay people, for example, do not regard acne vulgaris as a disease at all (Smith, 2002).

A second challenge is the fact that many skin diseases are chronic, and their burden is experienced more in living with the disease, than in dying from it. Thus, as with all chronic diseases, accurate measures of well-being are especially important for comprehensive assessments of burden of skin diseases. These measures—of impairment, disability, and handicap—can be difficult to develop, administer, and interpret, compared with more straightforward measures of incidence and mortality.

A third challenge relates to the complex relationship (especially for skin diseases) among impairment, disability, and handicap. For many—if not most—clinical conditions (Nease *et al*, 1995; Nichol *et al*, 1996), the severity of the impairment, or biological properties of the disease (e.g., the degree of coronary artery occlusion or of palmar hyperkeratosis) does not correlate in a predictable, linear fashion with the disability of the patient (e.g., the inability to run without angina or to use one's hands easily). Likewise, a degree of disability does not always handicap patients in the same way (e.g., a sedentary patient may not care to run, or a pianist may be devastated by being unable to use her hands). The complexity of this relationship, although true for most diseases, is perhaps most pronounced for skin diseases, which, because they can affect appearance and self-esteem, may handicap more than they impair or physically disable. Thus, a comprehensive assessment of skin disease burden requires a formal and explicit assessment of handicap. Such an assessment requires input from patients themselves, for clinicians are not able to predict accurately the quality of life effects of their patients' conditions (Parkerson *et al*, 1992).

State-of-the-art in Assessing Burden of Skin Disease

The papers in this focus issue of the *Journal* represent many approaches to measuring components of the burden of skin disease. The commentary by Karl Holubar provides a philosophical perspective [Holubar 0282], and Marie-Louise Johnson describes the seminal work she spearheaded on determining the prevalence of skin diseases by actual examinations performed as part of the first US Health and Nutrition Examining Survey of 1971–1974 [Johnson 0370]. A profile of current care for skin diseases in the US is provided by Robert Stern's analysis of data from the National Ambulatory Medical Care Survey [Stern 0291]. The difficulties of measurement of even the most straightforward assessments are illustrated by Valery and colleagues' documentation of the effect of examinations on the measured incidence rate of basal cell carcinoma [Valery 0332]. A population-based assessment of skin-related symptoms and effects on well-being is reported [Dalgard 0321], and additional papers describe measurement tools for aspects of well-being in dermatology patients, including quality of life [Lewis 0331], and utilities [Soon 0330]. Other papers address how well-being is affected by specific skin conditions [Stern 0266, de Korte 0313, Bishop 0293], including the relationship in patients with psoriasis between quality of life and clinical measures of disease severity [Heydendael 0333, Sampogna 0620].

Overall, these works represent significant progress by dermatologic researchers in conceptualizing and measuring burden of skin disease. The plethora of measurement tools illustrates in part the complexity and challenges inherent in measuring burden of skin disease that we describe above. Taken together, the papers describe a sequence of gathered evidence about skin disease burden, rather than a single metric or a single result. There is great interest in global metrics, however, given the national and international political and financial interest in the results of studies of burden of disease. Single numeric results are seductively "easy" to report and translate and seem—at least on the surface—straightforward and highly practical for making comparisons among burdens caused by different diseases. Given the multidimensional nature of the impacts of disease this apparent simplicity can be deceptive, and given the potential power of these measures, it is important for us to understand how the measures are designed and studied before accepting their results at face value (Nygaard, 2000). A typical example of such a "summary" measure of burden of disease is the Disability-Adjusted Life Year (DALY), the overall burden index used by the Global Burden of Disease study (Murray and Lopez, 1997). The DALY represents a method to quantify the health consequences of the years of life lived with a disability. It is a disability index that, for a given condition, reflects the probability of progressing to a disability, the duration of life lived with the disability, and the "value" of the disability (i.e., its severity in terms of activity restriction) (Cohen, 2000). Note that this measure of disease burden focuses exclusively on disability as the way a disease affects well-being. As we discussed above, accurate measures of the burden of skin diseases must assess not only disability but also handicap, or the effects of

a disease on patients' quality of life. Moreover, for the determination of disabilities related to different diseases, the Global Burden of Disease study used a panel of experts, who reviewed and compared disabilities related to the diseases in question, and rank-ordered them. As we discussed above, expert ratings may not correlate with ratings made by persons suffering from a disease (or even the general public).

The issues we have raised in this commentary should guide any consideration for the use of existing summary measures (such as DALY) for the assessment of the burden of skin diseases. In evaluating global measures we should ask *Were important components of disease burden adequate considered?* For example, the DALY measures disability only, not handicap. Measuring only the extent to which activity is restricted by a disease (disability) ignores a significant type of burden a disease can impose, namely, the effects of a disease on other aspects of quality of life such as psychological and social functioning. This oversight may particularly underestimate the burden of skin diseases, because of their frequent effects on these aspects of well-being. Second, *How was "severity" of burden weighted?* As we have noted, patients vary greatly in how they value health states, and experts may not accurately assess the experience of patients with a disease. Finally, we need to keep in mind that estimates of disease burden can vary substantially, depending on which summary measure is used (Gold and Muennig, 2002).

Conclusion

It seems likely that national and global efforts to monitor and compare overall health and individual diseases will increase. We in dermatology need to articulate important features about the burden of skin diseases, and promote rigorous scientific approaches to measuring this burden. It is clear that the burden of skin diseases can and should be assessed from multiple perspectives, including that of the patient, family, and society. Burden includes both economic and non-economic aspects, and a comprehensive assessment will require measurement of incidence and mortality as well as other dimensions of health, including patients' reports of disability and handicap.

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